# TEXAS TRAUMATIC BRAIN INJURY ADVISORY COUNCIL

## Meeting of April 20, 2001 Minutes

The Traumatic Brain Injury Advisory Council met in conference room M-653 in the Texas Department of Health Moreton Building from 10:00a.m. to 3:00p.m. at 1100 West 49<sup>th</sup> Street, Austin, Texas.

## **MEMBERS PRESENT:**

Mary Adams Jeff Latham

Cheryl Armoruso

Kimberly Arlinghaus, MD

Kate Burgess

Catherine Rich, JD

Jesse Seawell

Lesa Walker, MD

Mary Carlile, MD (for Susan Penfield, MD)

Nancy Childs, MD

Pat Craig, PhD

Les Young

Roger Webb

Walter High, PhD Adelaide Horn

(for Mary Beth O'Hanlon)

#### MEMBERS NOT PRESENT:

Rev. Kenneth Archer Carrie Morris

Tom Cowan Susan Penfield, MD Carol Gage Mary Beth O'Hanlon

Julia Hannay, PhD

## **TBI Project STAFF PRESENT:**

Larry Swift Susan Valley

Tina Sheffield

#### OTHER TDH STAFF PRESENT:

Kitten Holloway Tammy Sajak Sheila Tucker David Zane

#### WELCOME AND INTRODUCTIONS

Kim Arlinghaus called the meeting to order at 10:15a.m. and had everyone introduce themselves

#### PUBLIC COMMENT

No public comment

### **REVIEW OF MINUTES 1/26/01 MEETING\***

The minutes of the January 26, 2001 meeting were approved as presented.

#### CHAIRPERSON'S REPORT

At it's previous meeting, the TBIAC asked Chair Carrie Morris to share with the Texas Board of Health the Council's concerns about the proposed rules for the Trauma Registry. A copy of the testimony provided to the Board of Health and background documents is available. The Board added a specific reference to concussion as brain injury as requested. The other recommendations were not accepted by the Board. The Board asked staff to conduct a stakeholder process to review and recommend changes to the Trauma Registry, especially with regard to name reporting.

A Stakeholder planning committee has been formed. Carrie Morris, Larry Swift and Kathy Griffis-Bailey serve on the planning committee along with David Zane, Tammy Sajak, and Carol Write from Injury Epidemiology and Surveillance. Kitten Holloway from the Disease Prevention and Control Associateship Office chairs the planning committee and will facilitate the Stakeholder process. Three stakeholder meetings and one or two town meetings are expected by the end of August. The stakeholder groups identified include: the Texas Traumatic Brain Injury Advisory Council, the Brain Injury Association of Texas, Traumatic Brain Injury Model Systems, the Governor's EMS/Trauma Advisory Committee, the Texas Rehabilitation Commission, the Texas Trauma Coordinators Forum, the Texas Worker's Compensation Commission, the Texas Department of Health, Spinal Cord Injury Support Groups, the Texas Hospital Association and the Texas Rural Community Hospitals. The first stakeholder meeting will be held in Austin on May 23<sup>rd</sup>.

The Chair has appointed to the Trauma Registry Stakeholder group: Carrie Morris, Nancy Childs, and Mary Adams.

The Chair also reported that HB1676, which will prohibit insurers from excluding cognitive therapy for people with traumatic brain injury, has been recommended by the Committee on Insurance in the Texas House of Representatives and sent to the Calendars Committee. The Calendars Committee will decide whether and when to send the bill to the full house for a vote.

### DIRECTOR'S REPORT

Larry Swift introduced new staff: Susan Valley and Kathy Griffis-Bailey have joined the TBI Project as full time employees housed at the Health & Human Services Commission. Tina Sheffield is providing administrative support. We are happy to have them on board. The TBI Project Continuation Grant application has been submitted and discussions with federal grants management

staff are ongoing. The proposed contract with the Brain Injury Association of Texas is on hold until the amount of carry forward funds available is determined.

TBI Project PowerPoint slide presentation was given. The presentation discussed the magnitude of TBI as a public health problem, the causes and effects of TBI, the history of the TBIAC, and the need for long-term supports and services for people with a TBI and their families.

Feedback on presentation from council was:

- use quotes from survivors and families;
- include pictures of person with a TBI and their family;
- include definition of TBI;
- add demographic information regarding age and gender of persons injured;
- add information on substance abuse and family issues,
- discuss anatomy and physiology of the brain;
- discuss the greater impact and higher costs of second TBIs;
- show relative incidence and prevalence of muscular dystrophy and multiple sclerosis as compared with TBI;
- include ways to reduce the risk of TBI;
- discuss mild, moderate, and severe TBIs;
- and treatment approaches and long term care needs.

The PowerPoint slide show will be available through the TBI Office when suggested changes have been incorporated. A form will be developed to track the TBI Presentation's use and the types of audience to which it is delivered.

Kitten Holloway asked what is meant by long term care for people with TBI. Members provided many examples including: attendant care; transportation; supervision; supported employment; assistive equipment; housing; etc. There are many concerns from aging parents caring for their children with TBI regarding who is going to be there providing supports after their death. There is a huge gap in treatment; the more sever the injury the more difficult rehabilitation and long term support issues get. It is hard to get people in programs and severe TBI persons end up "warehoused" in nursing homes, with psychiatric patients, in jail, homeless, or living with families. Families are most frustrated by the lack of relevant timely information and education to help them assist their injured family member.

#### REPORT ON OLMSTEAD WORKSHOP

Addie Horn reported on implementation of the Olmstead and a conference she and Carrie Morris attended. The US Supreme Court on June 22, 1999, ruled that Americans with Disabilities Act requires states to provide treatment in community-based programs rather than in a segregated setting if the client and the treatment team want it and if the state provides appropriate community-based services. Texas is one of only four states with an implementation plan for meeting the requirements of Olmstead, Promoting Independence. SB367 and HB967 incorporate recommendations from the Promoting Independence plan. Other issues before the legislature relevant to Olmstead revolve around funding the waiting lists for community-based waiver programs needed to provide services outside institutions.

#### **COMMITTEE MEMBERSHIP & ACTIVITIES**

The committees met during lunch to review the work plan and develop mission statements for their committees.

#### COMMITTEE REPORTS

### **Identification Committee** – Walter High, Chair

Mission statement: To identify Texans with traumatic brain injury (TBI) utilizing the Texas Department of Health Trauma Registry, state service providers, associations, and self-identification for the purpose of creating access to needed services for person with TBI and their families.

### Barriers Committee - Mary Adams, Chair

Mission statement: Break Barriers to Services

Committee discussed the need to have people with TBI knowledge and experience participate on long term care committees and work groups. Committee suggested that "Case Coordinators" be changed to "Service Coordinators".

## **Education Committee** – Kim Arlinghaus, Acting Chair

Mission statement: Teach Texans about TBI

The committee explored a variety of ways to provide public information, get information and training to people with traumatic brain injury and their families, and to educate providers. Mass media, print and electronic educational tools were seen as the most effective means of raising public awareness. The committee recommends using existing materials to the extent possible to increase efficiency and to get materials out there faster. The Brain Injury Association of Texas has done significant work in identifying current materials.

#### TBI REGISTRY UP-DATE

Tammy Sajak gave a report on TBI 1998 Data Analysis

Council commented that the presentation included great charts/data interpretation. Council members made numerous requests for information in future reports and suggested changes in the current report. Tammy Sajak will revise the charts and report per Council's request. Other suggestions should be sent to Larry who will forward them to Tammy.

Because of some information in the report that may be confusing, the Council decided to withhold distribution until the revisions are made.

#### MOU BETWEEN TOH AND TBI ADVISORY COUNCIL

Mary Adams reported that the committee had sent a revised draft Memorandum of Understanding to David Zane for review. She asked that Council members send comments or suggestions for review. The committee hopes to have a final draft for Council consideration at the next Council meeting on July 19, 2001.

David Zane invited the Council to appoint one representative to help review PICARD software for calculating Bike injuries. The software will undergo a 6mo pilot test. A one hour conference will be held to obtain feedback on the software. Committee members interested should contact Carrie Morris. David Zane identified two traffic safety bills in which the Council may be interested. SB399 would prohibit anyone younger than eighteen years old from riding in the back of pickup trucks on public ways.

SB113 strengthens seat belt law for children by requiring all children up to age 16 to be restrained even if sitting in the rear seat.

#### **NEXT MEETING DATE AND AGENDA ITEMS**

The Council discussed alternative meeting times in order to have time for committees to meet before the Council meets. It was decided that the meetings will be on Fridays from 10:00 am to 5:00 pm with the committees meeting from 10 to noon.

The next meeting will be held from 10:00 am to 5:00 pm on Thursday, July 19<sup>th</sup> at the Dallas Los Colonias Marriot Hotel. This will precede the annual Texas Traumatic Brain Injury Conference, which will be held on July 20<sup>th</sup> and 21<sup>st</sup> at the same location. The TBIA Council will reimburse, within state policy, conference attendance expenses of Council members who are not employed by a state agency. Council members who plan to attend are encouraged to register and make hotel reservations early. For more information on the conference go to the Bait web site at: www.biatx.org.

### ADJOURN

The Traumatic Brain Injury Advisory Council Meeting adjourned at 2:55p.m.